



# EIGHT STEPS TO FUTURE CARE PLANNING FOR A LOVED ONE WITH SPECIAL NEEDS

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A child with disabilities requires special care now and in the future, but because there is so much to handle in the here and now, many parents and caregivers put off proper planning. They say, "I'll do it tomorrow," and before you know it many "tomorrows" have passed, the future is here, and little or no planning has occurred. Now what? How are clothing expenses going to be paid? Where will a family find affordable housing with supportive services for their loved one with special needs? What transportation is available? How does one put in place a care plan that will provide a full and rewarding life, yet still provide the safety net that needs to be in place? These are all important questions that need to be answered when a child is younger, rather than when he or she transitions into adulthood or when a parent/guardian passes away.

From education and housing to work and recreation, it can be overwhelming to think about all that needs to be done to develop a plan, making sure every aspect of life is covered. But if you take it one step at a time, it will get done. By this time next year, you can enter the holiday season with your mind at ease knowing you have begun to put a future care plan in place. Just follow the simple steps below. It takes action on your part, but if you stay committed to the timetable and persevere, the result will be a comprehensive future care plan.

I did it. As a matter of fact, I developed this eight-step process to help my parents plan for my sister, who was born with cerebral palsy. I watched my parents struggle with little help to plan her future. I noticed the families I work with professionally facing the same kind of fear, confusion and stress, so I wanted to develop a process that would work for other families who had a loved one with special needs. Over the years, it evolved to touch all aspects of life: family communication, legal considerations, potential government benefits, transition into adulthood, residential options, employment opportunities, recreational choices, and investment solutions. And with every step, the *abilities* of the individual with special needs are considered more than his or her disabilities, no matter the age. Let's get started.

## Assess Candidly

Make an honest assessment of future care needs in light of the entire family's make-up and financial situation. This may be the first time many families address head-on their dreams, goals, and fears for their loved one with special needs, but it's worth taking some time to think through it. It's the first big step in starting to recognize the work you must do to achieve peace of mind.

## Organize Thoroughly

Identify all the life needs for your loved one with a developmental disability, including a quality living environment, educational supports, medical needs and a wellness program, and recreational activities based upon the child's ability to support him or herself in the future. The family develops a vision of what they see for the individual in the different stages of their life. Then, quantify, through various calculations, a cash flow for the entire lifetime of the individual on your and their vision. Seek out a qualified financial planner to assist in this step if you're uncomfortable working with numbers. Stay committed to refining this Future Map each year, as the individual with special needs gets older and an understanding of their future needs are more apparent.



## **Explore Legal Options**

Legal considerations are an important part of the process. Certain legal documents are critical and can assist in speeding up or slowing down care for your loved one. As a parent, consider guardianship and a special needs trust as part of an estate plan. Finding an attorney who understands the specifics of drafting these types of documents is important. But before seeing an attorney, think through carefully all of the legal decisions that have to be made. Many families see an attorney for an initial consultation but never finish their estate plan because the decisions they need to make feel too daunting. Some parents have a hard time naming a family member or friend as a guardian to look after their child or a trustee to manage money matters if they die. It's also hard for them to grasp how much money to leave to their child with special needs for present and future care. Many times, parents can't decide how to best divide up their estate between their family member with special needs and the other children. If these decisions are made prior to the initial meeting with an attorney, it will help to keep the process moving, and you will see a future care plan come to fruition.

## **Tap into Government Services**

Government benefits may make up a large part of the required financial support for an individual with special needs, especially as they graduate into adulthood. Some parents are hesitant to tap into them, but they are essential for everything—from housing to healthcare to job coaching. Identify social service, community, and government programs that will enhance and support the future care plan, including school, recreation, specialized doctors, and even research protocols. Parents then can match up these needs with available government funding such as Supplemental Security Income and Medicaid. With housing and healthcare costs subsidized, parents will then need to reach into their pocket for such items as clothing, DVDs, recreational fees, and expenses over and above what the government programs will pay.

## **Document Important Information**

With a lot of the hard work under your belt, relax a bit and spend time simply recording important information about your loved one with the developmental disability. Document the individual's likes and dislikes, routines, and habits, so others can continue building your child's abilities and self-esteem. This information is key information required by teachers, camp counselors, caregivers, as well as future guardians. This step is one most often put off by parents because it can be time consuming, but this information can make a big difference in the future quality of life for your loved one. This process is often referred to as writing a special needs letter of intent. Guides with outlines to assist in compiling this information are available through various sources.

## **Transition into Adulthood**

In August, many families are preparing for another year of school, but for young adults with developmental disabilities who have completed their education in the spring, they no longer fall under the protection of state-mandated educational benefits, which typically end at age 21 or 22, depending upon the state you live in. They now need your help in finding a place to live, work, and play, in addition to seeking out transportation support. In the past, parents counted on the school system to lead the way in finding the right resources, but now all of a sudden, they feel as if they are on their own. The amount of research that is needed to find the right programs can be overwhelming. The best way to ease into this period of life is to develop a network of professionals to share important information, and, of course, plan early. Develop these relationships when your child is in his/her teenage years. Keep a binder with resources and support groups in your area that you can refer to when the time comes for the transition into adulthood. This is not a step that should be left until your child is 18 or 21. It should be an ongoing process throughout your child's lifetime.



A couple from northern Illinois waited until their only child turned 21 years old before they made arrangements for him to have a comfortable future. Through the guidance of specially trained special needs planners, the couple got their papers in order. The pair was able to identify their son's future needs, connect with the proper attorney to develop their estate documents, help their son find a fulfilling job, as well as help him connect with recreation programs. He is also learning to develop friendships beyond his immediate family. All of these areas are helping this man with a disability have a more fulfilled life, and his parents have achieved some peace of mind.

## Fund the Future

After you have a clear picture of the past and the future (as clear as it can be at the point at which you are), think about your own financial plan and how you can best coordinate it with your child's future care plan. At the start of the year, you calculated how much it would cost to maintain a certain quality of life for your child through the years, so you need to make sure there's money to pay for it.

Before you begin with the basic savings plan, assess other resources first. You might be surprised at the money available to you and your family. Start by investigating current benefits offered by your employer for dependents and for yourself. Examine disability, long-term care, life and health insurance policies to see how they would help your family in the event of any kind of tragedy. Next, understand the government funding available to meet your child's basic needs. When you see how much money is potentially available in the immediate future, then you can plan more long-term through various investment options.

Be sure any planned inheritance or beneficiary designations go directly to your child's special needs trust. Any sum of money larger than \$2,000 left in your loved one's name will threaten his or her access to those much-needed government benefits.

## Review and Renew

So now you have come full circle. Take some time to look back to see all that you have accomplished. Give yourself a pat on the back for making progress, and don't forget about respite to make sure everyone in the family is getting the care *they* need. Make a note or two on any changes you might want to make to your child's future care plan in the new year. You made it through the year and laid the foundation for your child to reach his or her fullest potential.

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